

OUR STORY

When Jonathan Tucker, Jr. was diagnosed with Alopecia areata at age 7, his dad shaved his head in support of his son.

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BALD is Beautiful

Helping Our Son Cope with Hair Loss

At first I thought my son had cut his own hair. He was taking a bath and I noticed a small bald patch on the back of his hairline. He promised me he had not, so I dismissed it and figured the hair would grow back. Six months later the hair had not grown back and I noticed a second spot. I called the pediatrician.

THE DIAGNOSIS

My son, Jonathan, was seven years old and in first grade when he was diagnosed with alopecia areata, an autoimmune disease that causes hair loss. By the second semester of second grade, the hair loss had become so severe our family decided to shave Jonathan's head. The longer hair length and "comb-overs" just weren't working anymore. To make Jonathan feel better, my husband agreed to shave his hair off too. None of us had realized how much of Jonathan's hair was actually gone until then. The patchy spots were a bit of a shock at first. Eventually Jonathan lost all of the hair on his head as well as eyebrows, arms, and legs.

Alopecia areata affects over five million people. It's not contagious, and it occurs in both sexes and all races and ages, but children are most commonly affected. The immune system, for unknown reasons, attacks the hair root and causes hair loss. Some people may lose all scalp hair (alopecia totalis) or all scalp and body hair (alopecia universalis). Currently, there is no cure. We tried various steroid creams and shots to "jump-start" Jonathan's immune system, but to no avail. Doctors informed us that other treatments were available, but in Jonathan's case, would probably not be effective. Only the body itself can eventually turn off the condition.

LEARNING TO COPE

Any mother (and father) of a child with a chronic condition asks herself what she could or could not have done to prevent the disease.

I am no different. I wonder if I nursed Jonathan long enough. I wonder if his immunizations had anything to do with his disease. Was he exposed to mold at some point? Does his allergy medication have anything to do with the hair loss? The questions and doubts are endless but I have learned that even if those things were true, I can't change them now. What I can do is help my child deal with the way he looks and help him understand that God knows what he is doing.



Jonathan, now in the fourth grade, began losing his hair when he was 7

AN OPEN APPROACH

We have been very proactive in handling Jonathan's disease. We feel it is best to tell people about his condition up front, rather than wait for questions. Most people who see him assume he is undergoing cancer treatment. The day before we shaved Jonathan's head, I met with his teachers to explain his condition. I shared a medical brochure about alopecia areata and answered their questions. I did the same with his school counselor. When he returned to school that Monday, Jonathan stood up in front of his class to explain why his hair was falling out and why he got to wear a hat to school.

Jonathan is now in fourth grade at WoodCreek Elementary School. At the beginning of each school year, he stands up in

front of the class to tell them about his condition. He likes to talk about famous athletes (like Charlie Villanueva of the Milwaukee Bucks, and Duncan Goodhew, an Olympic swimmer) who also have the disease. There are a few children in school who have laughed or called him names. Others have tried to take his hat. Of course Jonathan's feelings get hurt, but he knows that true friends won't treat him that way and true friends don't care if he's bald. He is fortunate to have many true friends.



At the beginning of each school year, Jonathan tells his class about his condition

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REACHING OUT TO OTHERS

It wasn't long after we shaved Jonathan's head that he told me a story about a young boy he met in the school bathroom. The boy asked Jonathan why he wore a hat. When Jonathan explained his disease, the boy told him that he had diabetes and felt different too. The two boys formed a bond that day. My husband and I have tried to encourage Jonathan to reach out to other children who are "different." Find the boy on the playground that others avoid. Talk to the girl in the wheelchair.

Our family is also involved in making others aware of alopecia areata. This year, I helped raise money to install a permanent sunshade over the playground equipment at WoodCreek Elementary. The shade will provide important protection from harmful UV rays as well as keep the kids cool. In addition to alopecia areata, Jonathan has eczema, so staying cool helps control his itchy skin.

ALOPECIA AREATA *What You Need to Know*

- It's a highly unpredictable autoimmune skin disease resulting in hair loss on the scalp and elsewhere.
- Typically starts with one or more small, round, smooth patches.
- It's not life-threatening, but is life-altering and can have a psychological impact on those affected.
- Affects 2% of the population overall, and five million in the US alone.
- Occurs in males and females of all ages and races, but is most common in younger persons.
- In all cases, hair regrowth may occur even without treatment and even after many years.

*information courtesy of naaf.org

National Alopecia Areata Foundation
naaf.org

Tortoise & Hair Fun Run
houstonnaaf5k.org

This June, we will co-chair the Tortoise & Hair™ 5K Run/1 Mile Walk in downtown Houston. The race will coincide with the 24th Annual National Alopecia Areata Foundation International Conference being held June 25-28 at the Hyatt Regency Houston. Our co-chairs, Jeff and Jennifer Magee, whose daughter, Elizabeth, also has alopecia areata, are Katy residents. Elizabeth is in the fourth grade at Jeanette Hayes Elementary School. Our goal is to raise awareness and money for research.

My husband and I are thankful that Jonathan is a healthy boy. Like others his age, he loves to play sports, is involved in many school activities, is a good student, and is not sure what to think about girls yet. We pray that he will continue to show compassion for others and find peace with how he is on the inside, rather than how he looks on the outside. **KM**